FULL COUNCIL MEETING MINUTES June 16, 2016 - 1:30 PM STATE COUNCIL FOR PERSONS WTH DISABILITIES Felton-Farmington Room, DelDOT Administration Building, Dover

PRESENT

Daniese McMullin-Powell, Chair; Jamie Wolfe, Vice-Chair; Deborah Bradl, DVI; Ray Brouillette, Easter Seals; Terri Hancharick, EPIC; Bonnie Hitch, DART; Jocelyn Langrehr, DOL/DVR; Pat Maichle, Parent; Dale Matusevich, DOE; Jim Miller, Polio/Post-Polio Support Group; William Payne, AAPD; Ann Phillips, DE Family Voices; Loretta Sarro, DOL/DVR DODHH; Lloyd Schmitz, Council of the Blind; Wendy Strauss, GACEC; Kyle Hodges, Staff; Amber Rivard, Support Staff and Jo Singles, Support Staff.

Interpreters: Deborah Monhollan/Peg Stewart

GUESTS

Victoria Counihan, Deputy Attorney General/Department of Justice Linda Osiecki, DelDOT Liz Suarez-Gonzalez, Jamie's attendant

CALL TO ORDER

Daniese called the meeting to order at 1:47 pm. Everyone introduced themselves.

ADDITION OR DELETIONS TO THE AGENDA

• CHOICES Presentation is deleted – Kyle stated that Nick sent an email explaining why he wanted to postpone this agenda item.

APPROVAL OF MINUTES

A motion was made by Jamie, seconded by Lloyd, and approved to accept the May 16, 2016 minutes as submitted.

BUSINESS

Amendments to SCPD By-Laws

Kyle referred to the following handouts: The SCPD By-Laws, Delaware Code re: SCPD and an email dated May 12, 2016 from Victoria with comments for consideration to the revised Bylaws. The revisions to the SCPD By-Laws (handout) were reviewed as follows:

- Article I The SCPD being a central state clearinghouse for information and data. Kyle stated
 that he thinks that SCPD is more of a resource of information. He noted that this could be
 changed in the Code next year. Jamie suggested checking with the Center for Disabilities
 Studies to see if they are considered a clearinghouse.
- Article II Wendy asked for clarification about the notification procedure regarding designees. Victoria commented that would be an internal operational procedure and Kyle agreed.

- Article IV The number of members at-large on the Executive Committee will remain at five (5). Another revision was a simple majority of the total membership shall constitute a quorum. Standing Committees - The Policy & Law Committee and the Brain Injury Committee shall have the authority to take action consistent with its charge without approval of the full Council. Nominating Committee will be appointed. A Deaf and Hard of Hearing Committee has been formed and meets on a regular basis; Kyle will provide a brief update on this Committee. The Director may act between meetings of the Council, Executive Committee, or other committees with jurisdiction, if the Director determines that prompt action is necessary subject to: 1)The Director's action is taken in consultation with the SCPD Chairperson, or if the Chairperson is unavailable, the Vice-Chairperson; 2) Notice of the action is shared within three (3) business days with the Executive Committee; and 3) Notice of the action is shared with the full Council at the next regular meeting. Victoria recommended using "authority" instead of "jurisdiction". Kyle explained that use of the word "jurisdiction" was the recommendation of the Executive Committee. Kyle asked if everyone was comfortable with the language; there were no objections.
- Article V Voting by telephone, email or proxy is not allowed under the State law and was deleted. Added: The Council may authorize modification of state meeting participating and voting standards and policies if necessary to provide a reasonable accommodation in conformity with federal law. Jamie asked if ADA laws would supersede State laws. Victoria explained that only State laws that conflict with ADA. Jamie commented that ADA is broader than program accessibility. Victoria stated that she would be willing to check with an ADA law expert (Brian Hartman) on how it applies to the situation. Kyle noted that persons with disabilities need special accommodations at times. He stated that this will be further addressed in the State law next year. No objections were made with the new language.
- Article VI Robert's Rules of Order was deleted and the following added: Amendments to these
 by-laws may be adopted by a quorum of the full Council at any duly authorized official Council
 meeting and must be in compliance with any State legislation affecting this Council. Bill asked
 about the replacement for the Robert's Rules of Order. Victoria explained that this is covered
 under the Administrative Procedures Act.
- Kyle noted that the Employment First Oversight Commission is not included as a Standing Committee because it is determined by statute, but is referenced under Purpose and Duties.

Pat Maichle made a motion to approve the revisions to the By-Laws as written. Ann made a second motion and Lloyd made a third motion. Everyone approved the motion, with no one opposing or abstaining. Kyle thanked the Executive Committee and Victoria for their input.

SCPD Elections

Jamie will be the new Chairperson of the SCPD and Daniese will be the Vice-Chairperson. The Executive Committee will consist of the following members-at-large: Brian, Wendy, Nick, Ann and Lloyd. Daniese asked if there were any nominations and none were made. A motion was made to approve by Pat and a second motion was made by Jim Miller. Everyone approved, except for Daniese, Jamie, Wendy, Ann and Lloyd who abstained from voting since they were in the running.

<u>Transportation Issues</u>

Jamie spoke about her experience and comments from others that the quality of service has decreased since fares have increased. She gave several examples, including coordination of trips, and going to the drop-off spot instead of pick-up location. She also spoke about the impact of the fare increase for persons with disabilities. Kyle asked about the correlation between the fare increase and decreased quality of service. Bonnie stated that the actual numbers of complaints have been decreasing. She

said that she could review numbers, but they are not seeing or hearing this. Lloyd commented that most customers only know the reservation number. He asked if someone calls the reservation number with a complaint, could they be transferred instead of getting another telephone number to call. Bonnie will follow-up on this. Bonnie added that reservationists have access to the computer module where complaints are logged. She will follow-up on this process. Pat and some others spoke about complaints about the cost, the fear of not being able to afford the increases, and having to stay in their homes; this includes needed trips to the grocery stores and pharmacies. Jim commented about his experience in deciding whether or not to attend a meeting when the cost is \$24 round trip. He noted that having these meetings in Kent County have affected his and Lloyd's ability in being able to afford to attending meetings in Kent and New Castle Counties since they both live in Sussex County. Kyle noted that Jo and/or Amber can distribute Dart tickets for people to attend meetings. Jim, Lloyd and Jamie said that this assistance was very helpful. Ann commented that she is hearing from young adults transitioning into adult services that they cannot afford to pay for Paratransit and other services they received as children. Bonnie noted that the fare increase went through the State Legislature. She added that while many concerns were expressed, the increase was approved. Bonnie asked that people voice their concerns for the purpose of documentation and they will be forwarded to the Secretary of DelDOT. Bonnie added that people should call Customer Relations directly or go online. Bonnie will also accept complaints if people are not comfortable in the other ways. Jamie commented that she has received conflicting amounts on payment due when making the reservation and when she actually gets picked up. Bonnie explained that what the reservationist sees on the screen also prints out on the manifest for the driver. Bonnie added that they have the ability to not charge for a trip when there is a discrepancy, but that people need to call and let them know. Bonnie said that they could also send out a bulletin to drivers stressing that they need to let dispatch know about issues. Daniese noted that an increase in fares starts in July. Jamie asked if riders are getting notification about the price increase, and Bonnie confirmed that they receive notification.

Community-Based Services Issues

Ann spoke about issues she has experienced with home health aides not being allowed to perform certain procedures that they previously were doing because they are now considered medical procedures. The home health agency is being told that they are violating the nursing regulation. Also, they are not allowed to give verbal cues. Ann is concerned about people who cannot do this themselves and her concern about the amount of work going into keeping people in the community and out of nursing homes. People are losing the tools needed to stay in the community. Ann added that she cannot find the regulation that specifically addresses these issues. Ann stated that she contacted other home health agencies and found out that they are under the same restrictions. Ann added that she like to work with the agencies so she will have backup service if someone cancels. She discovered that the only time the home health aide can give a reminder is if the person needing the reminder is without any cognitive disability. She said we talk about self-directed care for all people with disabilities so why would their cognitive disability exclude them from that allowance.

Jamie recommended having an ad hoc committee to look at these issues. Kyle stated that there is a combination of laws and regulations that need to be reviewed, including revisiting the Nurse Practice Act. A law addressing this was passed in 2004, but apparently is not working. Ann spoke about people who do not attend meetings and do not know who to call about these issues. Pat stated that some of these issues are about insurance liability. Ray commented that with the personal attendant services and interim services that they have provided in 2012, one of the first questions was "are they going to be distributing and administering medications?" Since they are considered a non-medical process, they are not allowed. Daniese commented that other states have changed this. She stated that the Nurse Practice Act needs to be amended so that a nurse can instruct a caregiver on how to do particular procedures one-on-one. Ann commented that her agency was doing this, but have been told by the

Nursing Board that they are in violation. She was told that sending a nurse to do the procedure was not cost effective. Ann said that she was left with finding a solution herself. Cueing is not addressed in the Nurse Practice Act. Jamie asked if Senator Blevins (original sponsor of the Nurse Practice Act) and the Nursing Board could attend the next meeting in September to discuss this and research could be done during the summer.

Ann spoke about the lack of Durable Medical Equipment providers in Delaware. The providers say it is not cost effective for them to sell or repair equipment based on the Medicaid reimbursement rates. The response she received from Medicaid was that it was a national problem. The MCO's should have provider information on their website and they do not. Ann found one provider who is doing a really bad job and they are backed up with work. This issue does not give people a choice. Ann sees this as another way that health care is being jeopardized. Many people do not know whom to call when they face this issue. Daniese commented that people are required to get prescriptions from doctors for all repairs on their wheelchair, including seat belt replacement. This topic will be included in the ad hoc committee's work. Jamie and/or Kyle will send out an email regarding the ad hoc committee.

Jamie spoke about the lack of backup support in getting personal attendants. Terri spoke about a new platform called MySupport.com (handout). The program offers one-stop interface of finding the right worked for the right client. This platform is active in California, Iowa and New Jersey. Terri would like to have it in Delaware. There have been discussions with Secretary Landgraf (DHSS) and Steve Groff (DMMA). Terri commented that this would help with emergency backup issues. Ray commented that the case manager would have to approve the emergency backup and agree to pay for this service, rather than Easter Seals or JEVS. Jamie noted that this would work on a Monday through Friday basis, but not for weekends. Terri will keep the Council informed on the progress of MySupport.com in Delaware.

Jamie spoke about the person receiving personal attendant services receiving training on how to work with personal attendants and handling issues with personal attendants. This training would alleviate some problems that occur. Ray suggested looking at what is currently being provided and find out if it is adequate or not. If not, identify the areas that need to be strengthened. He noted that Attendant Services has changed over the years, along with increased numbers of participants. He suggested contacting Kim DeShields or Tom Barlow. Ray noted that Personal Attendant Services is not licensed.

Agreement was made to speak with Brian first and then decide next steps. An ad hoc committee will then be formed. Potential representation from the following agencies: Debbie Gottschalk/DHSS and Ann Woolfolk (AG/DHSS), Lisa Bond (DSAAPD), Carolyn Fredricks (Modern Maturity Center/Chair of the Council on Aging and Adults with Physical Disabilities), Kathleen Mahoney (DMMA), Kim DeShields (Easter Seals), JEVS, representative from the Insurance Commissioner's Office, Tanner (Senator Hall-Long's legislative liaison), Terry Macy/DDDS. Kyle and/or Jamie will send out a broad-based email about supporting people in the community, and review laws and regulations that are restrictive. Pat noted that DHSS may have already done this research when working on Community Rule.

Ann spoke about threatening statements in fine print at the bottom of the paperwork that gets signed off by clients that states that if their care costs more, then they may have to go to a nursing home and if they do not want to go to a nursing home, then they understand that they may have to lose Medicaid to stay in the community. She has been told that this has since been removed. There was concern about the people who do not know how to handle this and just accept what they are told. Ann suggested that those who interested participate in the monthly conference call with the MCOs and Medicaid representatives. Kyle will forward the information to call-in to everyone.

Committee Reports

Kyle stated that this will be a Standing Agenda item. The final minutes can be found on the State Public Calendar (listed by each meeting date). They were previously on the SCPD website, but DTI removed them when the website was revised. He will look into having them put on the website again. Hard copies are available upon request.

Policy & Law Committee:

- H.B. 200 on Accessible Parking. There is a Substitute Bill and an Amendment. It was supposed to be heard last week, but that never happened. He will continue to work on moving it forward. Pat thanked Kyle for all his work and perseverance on this. Bill asked if there was a way to get this information in the newspaper. Kyle commented that he thought it would be difficult to do this year.

In the interest of time, Kyle will send an email with updates on legislation. Lloyd thanked Kyle for his work regarding the creation of an advisory task force to look at new voting machines. Kyle commented that accessibility is an important issue when choosing voting machines. He contacted Senator Poore to have representation on the Task Force and she was able to do so that same day. Kyle added that he sent an email to Senator Poore thanking her for such a quick response.

OTHER BUSINESS

None

ANNOUCEMENTS

Kyle stated that John McNeal has been hospitalized and keep him in their thoughts. He also thanked Daniese for serving as Chairperson since 2004. Everyone applauded in appreciation. Daniese congratulated Jamie as the new Chairperson.

Jamie announced that the S.B. 230 Supported Decision-Making will be on heard on Wednesday on the Senate Floor.

ADJOURNMENT

The meeting was adjourned at 3:39 pm.

Respectfully submitted,

Jo Singles Administrative Specialist

SCPD/min/jun16